# Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in hospice and palliative care, and in the quality of end-of-life care in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

Compiled & Annotated by Barry R. Ashpole

Goals and mission of hospice: Scroll down to <u>Specialist Publications</u> and 'CPR and hospice: Incompatible goals, irreconcilable differences' (p.14), in *Progress in Palliative Care*.

# Canada

### More hospitals welcoming family during patient resuscitation

ALBERTA | CTV News – 7 August 2014 – When a code blue is announced in hospital and a resuscitation team rushes to a patient's side, tradition has dictated that family members get out of the way, both to protect their sensibilities and to give doctors and nurses the room and concentration needed to perform life-saving care. But that notion of separating patient and loved ones is slowly being replaced by a new model of care, in which family members are given the option – and sometimes even encouragement – to remain near the bedside, where their presence is viewed as beneficial. Among centres embracing the idea is Calgary's recently opened acute-care hospital, South Health Campus, where staff make sure family members know they are welcome to be present during a resuscitation if they so choose. <a href="http://www.ctvnews.ca/health/more-hospitals-welcoming-family-during-patient-resuscitation-1.1949413">http://www.ctvnews.ca/health/more-hospitals-welcoming-family-during-patient-resuscitation-1.1949413</a>

Noted in Media Watch, 17 March 2014, #349 (p.16):

YALE JOURNAL OF BIOLOGY & MEDICINE, 2014;87(1):63-72. 'Family presence during resuscitation: Attitudes of Yale-New Haven hospital staff.' A novel paradigm of patient-and family-centered care has been promoted and adopted by many parties in the U.S. This new attitude emphasizes the role of the family in the care of the patient. Seventy-seven percent of staff members favored allowing the option of family presence during resuscitation. Seventy-six percent of staff members believed that family members would want to be present during their loved one's resuscitation. <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3941452/">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3941452/</a>

Noted in Media Watch, 18 March 2013, #297 (p.4):

NEW ENGLAND JOURNAL OF MEDICINE | Online – 14 March 2013 – 'Family presence during cardiopulmonary resuscitation.' Relatives [i.e., study participants] who did not witness CPR had symptoms of anxiety and depression more frequently than those who did witness CPR. Family-witnessed CPR did not affect resuscitation characteristics, patient survival, or the level of emotional stress in the medical team, and also did not result in medico-legal claims. <a href="http://www.nejm.org/doi/full/10.1056/NEJMoa1203366?query=featured\_home">http://www.nejm.org/doi/full/10.1056/NEJMoa1203366?query=featured\_home</a>

# Dalhousie residents demand to keep palliative care beds

NEW BRUNSWICK | CBC News (Dalhousie) – 6 August 2014 – Dalhousie-area residents are upset about the loss of four palliative care beds at the St. Joseph Community Health Centre in the northern town. The beds are closed for several months each year to save money, but the Vitalité Health Network announced it plans to shut them down permanently, reducing the number of end-of-life care spots in the region to six from 10. Vitalité officials say the decision to eliminate the palliative care beds is about efficiency. <a href="http://www.cbc.ca/news/canada/new-brunswick/dalhousie-residents-demand-to-keep-palliative-care-beds-1.2729087">http://www.cbc.ca/news/canada/new-brunswick/dalhousie-residents-demand-to-keep-palliative-care-beds-1.2729087</a>

Noted in Media Watch, 27 September 2010, #168 (p.1):

■ NEW BRUNSWICK | CBC News (Saint John) – 22 September 2010 – 'Hospices needed province-wide: Doctor.' New Brunswick's first residential hospice is set to open in Saint John, but health-care professionals ... say the need for such facilities is critical across the province. <a href="http://www.cbc.ca/canada/new-brunswick/story/2010/09/22/nb-hospice-need-moncton.html">http://www.cbc.ca/canada/new-brunswick/story/2010/09/22/nb-hospice-need-moncton.html</a>

### Mobile palliative programs give "end-of-life-care" to homeless

ONTARIO | CTV News (Toronto) – 3 August 2014 – They're too often the forgotten people – or the ones many of us turn a blind eye to as we pass a street corner where they might implore us for extra change: the homeless living rough outside through all kinds of weather or those precariously housed in a cot-for-the-night shelter or a decaying rooming house. But what happens when these people are dying? Where do they find care in their final days? "Being sick is hard. Being sick and homeless can be even harder," Dr. Naheed Dosani, a palliative care specialist at St. Michael's Hospital in Toronto, says with obvious understatement. Dosani, a member of a large network of inner-city health physicians, is part of a new program that takes end-of-life care to the homeless and vulnerably housed wherever they are situated. Called PEACH – for Palliative Education & Care for the Homeless – the watchword of the mobile program is to give individuals the dignity of choosing where they receive medical and supportive care, and hopefully where they will able to die. <a href="http://www.ctvnews.ca/canada/mobile-palliative-programs-give-end-of-life-care-to-homeless-1.1944757">http://www.ctvnews.ca/canada/mobile-palliative-programs-give-end-of-life-care-to-homeless-1.1944757</a>

Noted in Media Watch, 15 November 2010, #175 (p.7):

CANADIAN HEALTHCARE NETWORK | Online – 9 November 2010 – 'End-of-life care for homeless.' For homeless and marginalized people on the streets of Halifax, Nova Scotia, there's a good chance that, when their time comes, they may not have the opportunity to choose the kind of end of life that care that they would prefer. Monica Flinn, RN, is part of a group that is working to change that ... with the Mobile Outreach Street Health Program ... <a href="http://www.canadianhealthcarenetwork.ca/nurses/news/movers-shakers/monica-flinn-end-of-life-care-for-homeless-6956">http://www.canadianhealthcarenetwork.ca/nurses/news/movers-shakers/monica-flinn-end-of-life-care-for-homeless-6956</a>

**N.B.** Several articles on end-of-life care for the homeless are noted in Media Watch, 3 February 2014, #343 (p.4). In the U.K., Marie Curie Cancer, with St. Mungo's Broadway, published 'Homelessness and End-of-Life Care.' <a href="http://www.mariecurie.org.uk/Documents/Commissioners-and-referrers/HomelessReport.pdf">http://www.mariecurie.org.uk/Documents/Commissioners-and-referrers/HomelessReport.pdf</a> [Noted in Media Watch, 20 May 2013, #306 (p.7)]. The Summer 2014 issue of *European Network of Homeless Health Worker*, which includes an article on homelessness, ageing and dying (p.7) is available at: <a href="http://www.sophie-project.eu/pdf/ENHW">http://www.sophie-project.eu/pdf/ENHW</a> 2014.pdf

### **Media Watch Online**

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.16.

# U.S.A.

### House calls keep people out of nursing homes and save money

NATIONAL PUBLIC RADIO | Online – 7 August 2014 – When it comes to reining in medical costs, delivering more health care and bringing it right to the patient's home can, for a select group of patients, save money. These particular patients are elders struggling with multiple chronic medical conditions, such as congestive heart failure, stroke, diabetes or dementia. They make up just 5% of the people on Medicare, but they account for about half of all Medicare spending. In a study by MedStar Washington Hospital Center in Washington DC, 722 such patients were provided with home-based health care delivered by a team: a physician, a nurse practitioner, licensed practical nurses and social workers. The visits were frequent and there was someone on call for urgent situations 24/7. The study found patients who received this home-based care had 20% fewer ER visits, 9% fewer hospitalizations, and 27% fewer stays in a nursing home than similar Medicare patients in the control group. The death rate among these very vulnerable patients was high, but was about the same for both the study group and the control group. In a two-year period, Medicare saved \$8,477 for each patient getting home-based care. http://www.npr.org/blogs/health/2014/08/07/338393136/house-calls-keep-people-out-of-nursing-homes-and-save-money

 'Effects of home-based primary care on Medicare costs in high-risk elders,' Journal of the American Geriatrics Society, 18 July 2014. http://onlinelibrary.wiley.com/doi/10.1111/jgs.12974/pdf

Selected articles on the economies and efficiencies of house calls noted in past issues of Media Watch:

- THE NEW YORK TIMES | Online 19 April 2014 'House calls are making a comeback.' A relic from the medical past the house call is returning to favor as part of some hospitals' palliative care programs, which are sending teams of physicians, nurses, social workers, chaplains and other workers to patients' homes after they are discharged. The goal is twofold: to provide better treatment and to cut costs. [Noted in Media Watch, 21 April 2014, #354 (p.2)] <a href="http://www.nytimes.com/2014/04/20/business/house-calls-are-making-a-comeback.html?ref=health%">http://www.nytimes.com/2014/04/20/business/house-calls-are-making-a-comeback.html?ref=health%</a> r=0
- THE WALL STREET JOURNAL | Online 4 February 2013 'Hospitals try house calls to cut costs, admissions.' Health-care providers are bringing back revamped versions of a time-honored practice: the house call. [Noted in Media Watch, 11 February 2013, #292 (p.3)] <a href="http://online.wsj.com/article/SB10001424127887324610504578278102547802848.html">http://online.wsj.com/article/SB10001424127887324610504578278102547802848.html</a>
- MASSACHUSETTS | Boston Globe 1 July 2012 'Can house calls cut health costs?' Daniel Oates, a Boston Medical Center geriatrician believes home visits provide more personalized, consistent care to people who might not otherwise see a doctor and can prevent hospitalizations or delay a move to a nursing home. [Noted in Media Watch, 2 July 2012, #260 (p.2)] <a href="http://bostonglobe.com/lifestyle/health-wellness/2012/07/01/can-house-calls-cut-health-care-costs-house-calls-boston-medical-center-program-testing-home-care-for-homebound-seniors/s6jidObrL7oC43lkTDK8dL/story.html">http://bostonglobe.com/lifestyle/health-wellness/2012/07/01/can-house-calls-cut-health-care-costs-house-calls-boston-medical-center-program-testing-home-care-for-homebound-seniors/s6jidObrL7oC43lkTDK8dL/story.html</a>

# Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

# "Right to try" measure to be considered in Arizona, other states

ARIZONA | The Washington Post – 6 August 2014 – Arizona could become the latest state to allow those who are terminally ill to try experimental treatment not yet approved by the Federal Drug Administration. This "right to try" ballot initiative will be put before voters in November. If passed, Arizona would join Colorado, Louisiana and Missouri in allowing the practice... There are between there 500,000 to 1 million people with terminal illness in the U.S., said Victor Riches, a spokesperson for the Goldwater Institute, which is pushing for the measure in Arizona and working with potential sponsors for bills in other states in 2015. So far, the bills have been "very, very similar," he said, requiring any drugs taken to have at least passed a Phase 1 clinical trial and be part of on-going clinical trials. They protect doctors who recommend experimental treatment with any terminally ill patients. <a href="http://www.washingtonpost.com/blogs/govbeat/wp/2014/08/06/right-to-try-measure-to-be-considered-in-arizona-other-states/">http://www.washingtonpost.com/blogs/govbeat/wp/2014/08/06/right-to-try-measure-to-be-considered-in-arizona-other-states/</a>

Noted in Media Watch, 30 June 2014, #364 (p.15):

SCIENCE, 2014;344(6190):13229. "Right to try" laws bypass Federal Drug Administration for last-ditch treatments.' Several state legislatures, prodded by desperately ill patients and a libertarian think tank, are defying federal regulators to make experimental drugs available to terminally ill patients outside of clinical trials. The new laws, called "Right to Try," went on the books in two states last month and are being considered in several others. <a href="http://www.sciencemag.org/content/344/6190/1329.short">http://www.sciencemag.org/content/344/6190/1329.short</a>

### Rising rates of hospice discharge in U.S. raise questions about quality of care

THE WASHINGTON POST | Online - 6 August 2014 - At hundreds of U.S. hospices, more than one in three patients are dropping the service before dying, research shows, a sign of trouble in an industry supposed to care for patients until death. When that many patients are leaving a hospice alive, experts said, the agencies are likely to be either driving them away with inadequate care or enrolling patients who aren't really dying in order to pad profits. It is normal for a hospice to release a small portion of patients before death – about 15% has been typical, often because a patient's health unexpectedly improves. But researchers found at some hospices, and particularly at new, forprofit companies, the rate of patients leaving hospice care alive is double that level or more. The number of "hospice survivors" was especially high ... in Mississippi, where 41% of hospice patients were discharged

alive, and Alabama, where 35% were. http://www.washingtonpost.com/business/economy/leaving-hospice-care-alive-rising-rates-of-live-discharge-in-the-us-raise-questions-about-quality-of-care/2014/08/06/13a4e7a0-175e-11e4-9e3b-7f2f110c6265\_story.html

### **Specialist Publications**

'For-profit Medicare home health agencies' costs appear higher and quality appears lower compared to non-profit agencies' (p.10), in *Health Affairs*.

'Can hospices predict which patients will die within six months?' (p.12), in *Journal of Palliative Medicine*.

1. 'A national study of live discharges from hospice,' *Journal of Palliative Medicine*, 7 August 2014. <a href="http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0595">http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0595</a>

# Of related interest:

FLORIDA | The Tampa Bay Times – 6 August 2014 – 'Hillsborough hospice group cuts 89 jobs.' The parent company of LifePath Hospice eliminated 89 jobs this week, citing declining government reimbursements, costly regulatory changes and uncertainty amid expected changes to the hospice payment system. <a href="http://www.tampabay.com/news/health/hillsborough-hospice-group-cuts-89-jobs/2191718">http://www.tampabay.com/news/health/hillsborough-hospice-group-cuts-89-jobs/2191718</a>

Cont.

MCKNIGHTS | Online – 6 August 2014 – 'Introduced bill calls for mandated hospice in-spections.' Hospices would need to undergo an inspection every three years under a bill introduced by a New York congressman. Skilled nursing facilities already are subject to required surveys in order to maintain Medicare and Medicaid certification under the Social Security Act. <a href="http://www.mcknights.com/introduced-bill-calls-for-mandated-hospice-inspections/article/364759/">http://www.mcknights.com/introduced-bill-calls-for-mandated-hospice-inspections/article/364759/</a>

### About half of heart procedure patients make end-of-life plans

REUTERS | Online – 5 August 2014 – Less than half of the patients who underwent a risky heart surgery at one medical center completed advanced directives to guide their care in the event they could no longer articulate their wishes, according to a new study. In addition to ensuring patients receive care that's in line with their wishes, the study's senior author IDr. Paul Mueller, chair of general internal medicine at the Mayo Clinic in Rochester, Minnesota] said advanced directives reduce the burden on family members who would otherwise make those decisions. There has been increasing attention in recent years toward encouraging people to make their end-of-life preferences known... But researchers have found the

message is only getting across consistently to patients with certain diseases or under certain circumstances, and even then the rules and paperwork are not always clear. <a href="http://uk.reuters.com/article/2014/08/05/us-advance-directive-heart-surgery-idukkbnog526620140805">http://uk.reuters.com/article/2014/08/05/us-advance-directive-heart-surgery-idukkbnog526620140805</a>

### **Specialist Publications**

'Shared decision-making about end-of-life care for heart failure patients with an implantable cardioverter defibrillator: A national cohort study' (p.12), in *Journal of Cardiac Failure*.

1. 'Advance directives of patients with high-risk or inoperable aortic stenosis,' *JAMA Internal Medicine*, 4 August 2014. <a href="http://archinte.jamanetwork.com/article.aspx?articleid=1892180">http://archinte.jamanetwork.com/article.aspx?articleid=1892180</a>

Noted in Media Watch, 9 June 2014, #361 (p.3 & p.15):

- US NEWS & WORLD REPORT | Online 4 June 2014 'Many with heart failure aren't told about end-of-life care: Study.' The investigators found only 12% [of health care providers survey] said that they had routine yearly discussions with heart failure patients about end-of-life care, as recommended by the American Heart Association. The study authors found 52% of the healthcare providers were hesitant to mention end-of-life care to patients. Of those, 21% believed patients weren't ready to talk about the topic, 11% felt uncomfortable bringing it up, 9% said they were concerned about destroying a patient's sense of hope, and 8% said they didn't have time. <a href="http://health.usnews.com/health-news/articles/2014/06/04/many-with-heart-failure-arent-told-about-end-of-life-care-study">http://health.usnews.com/health-news/articles/2014/06/04/many-with-heart-failure-arent-told-about-end-of-life-care-study</a>
- MEDICAL DAILY | Online 4 June 2014 'End-of-life care: Doctors reluctant to discuss issue with chronic heart condition patients.' About 720,000 people have heart attacks in the U.S. every year and one in every four deaths is related to heart diseases, according to the Centers for Disease Control & Prevention. Even though it is an acknowledged fact that heart failure cases will be better off with palliative care, it is not enforced in all cases, mainly due to a lack of communication. <a href="https://www.medicaldaily.com/end-life-care-doctors-reluctant-discuss-issue-chronic-heart-condition-patients-286324">https://www.medicaldaily.com/end-life-care-doctors-reluctant-discuss-issue-chronic-heart-condition-patients-286324</a>

# Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <a href="http://www.pcn-e.com/community/pg/file/owner/MediaWatch">http://www.pcn-e.com/community/pg/file/owner/MediaWatch</a>

### "Market" trends

### Marin hospice is talking about joining Sutter

CALIFORNIA | Marin Independent Journal (St. Rafael) – 2 August 2014 – One of Marin's most respected non-profits, Hospice By The Bay – formerly Hospice of Marin – may soon surrender its independence. The board of America's second-oldest hospice is considering a "strategic alliance" with another institution. A likely option sees the organization being absorbed by Sacramento-based [for-profit] Sutter Health. The local hospice's board hasn't made a final decision but it has already vetted merger options. One motivation, according to Hospice board president Dennis Gilardi, surrounds mammoth changes facing America's health industry, including hospice providers. Over half America's hospice operations are for-profit. Expert at marketing, these bottom-line corporations put pressure on people-oriented operations like Hospice By The Bay. Some fear Sutter, with its bottom-line corporate culture, would be hard-pressed to retain Hospice's culture of quality. <a href="http://www.marinij.com/ci\_26261454/dick-spotswood-marin-hospice-is-talking-about-joining">http://www.marinij.com/ci\_26261454/dick-spotswood-marin-hospice-is-talking-about-joining</a>

Noted in Media Watch, 23 April 2014, #259 (p.2):

■ CALIFORNIA | *Modesto Bee* − 20 April 2012 − 'To aid patients, Sutter Health employees queried about end-of-life care wishes.' Palliative care teams at the region's seven Sutter Health hospitals have spent time promoting their "Having the Talk" program among Sutter employees, educating them on the importance of talking to their families about their end-of-life care wishes, then putting in place the appropriate documents that set out those preferences. The campaign hasn't targeted patients but rather the employees and medical professionals themselves and their families. <a href="http://www.modbee.com/2012/04/20/2165735/to-aid-patients-sutter-health.html">http://www.modbee.com/2012/04/20/2165735/to-aid-patients-sutter-health.html</a>

# **International**

#### Elder care in Australia

### Report highlights increasing demand in aged care

AUSTRALIA | ProBono Australia – 7 August 2014 – A new report has found more older Australians are accessing aged-care services, with the greatest increase in services delivered to people in their homes and in the community. The report found 29% of people aged 65 years and over accessed aged care services in 2010-2011, up from 26% in 2002-2003. The greatest increase was in community care programs, which were used by 79% of all aged-care clients in 2010-2011, up from 76% in 2002-2003. <a href="http://www.probonoaustralia.com.au/news/2014/08/report-highlights-increasing-demand-aged-care#">http://www.probonoaustralia.com.au/news/2014/08/report-highlights-increasing-demand-aged-care#</a>

1. 'Patterns in use of aged care: 2002-2003 to 2010-2011,' Australian Institute of Health & Welfare, August 2014. <a href="http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129548006">http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129548006</a>

### Elder care in Singapore

### New guidelines for home care providers to be finalised by end of the year

SINGAPORE | *The Straits Times* – 5 August 2014 – The Health Ministry is working with home care providers to develop and introduce a set of guidelines to boost the quality of services. There are currently no specific Ministry guidelines dealing with home care. Those who need home care are typically too frail to leave their homes for medical appointments, and may need help with daily activities like eating or bathing. In March, the Health Ministry had announced that it is planning for a capacity of 10,000 home medical and nursing care spaces by 2020, and 7,500 for home personal care. <a href="http://www.straitstimes.com/news/singapore/health/story/new-guidelines-home-care-providers-be-finalised-end-the-year-20140805">http://www.straitstimes.com/news/singapore/health/story/new-guidelines-home-care-providers-be-finalised-end-the-year-20140805</a>

### End-of-life care in Ireland

# Six-month [medical] card renewal rule is blasted "inhuman"

IRELAND | *The Independent* (Dublin) – 4 August 2014 – Current rules that force people who are dying to renew their medical card every six months are inhuman and need to be changed, a report has warned. The terminally ill should be granted a card for a year or have it automatically renewed, based on a covering letter from their GP or consultant. The call was made in a report on end-of-life and palliative care in Ireland from the Joint Oireachtas Committee on Health & Children. The report quoted consultant in palliative care, Dr. Paul Cregan, who said: "If we feel a person will die within six months, then he or she will qualify for the service. However, we are not going to get it right every time. "Based on unpublished research, we believe that, approximately 20pc of the time, the six month period will be over-run. We are currently running over by one or two months. To ask a person within a month or two of dying to reapply for a medical card on a means test, rather than discretionary basis, is inhuman." <a href="http://www.independent.ie/irishnews/health/sixmonth-card-renewal-rule-is-blasted-inhuman-30477664.html">http://www.independent.ie/irishnews/health/sixmonth-card-renewal-rule-is-blasted-inhuman-30477664.html</a>

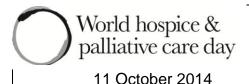
 'Report on End-of-Life and Palliative Care in Ireland,' Joint Oireachtas Committee on Health & Children, July 2014. [Noted in Media Watch, 21 July 2014, #367 (p.4)] <a href="http://www.oireachtas.ie/parliament/oireachtasbusiness/committees\_list/health-and-children/reports/">http://www.oireachtas.ie/parliament/oireachtasbusiness/committees\_list/health-and-children/reports/</a>

#### Palliative care fails some Māori

NEW ZEALAND | Radio New Zealand (Auckland) – 4 August 2014 – New research shows whānau [extended family], Māori face barriers in accessing end-of-life care, due to the sector's inability to respond to cultural needs. The University of Auckland research, Kia Mau te Kahu Whakamauru, interviewed 21 whānau about their experiences with accessing care, as well as talking to workers within the health sector. Although there's an increase in older Māori people, the study found there's a low number of tangata whenua [i.e., the indigenous peoples of New Zealand] going into palliative care services such as hospices. The lead researcher, Ngāpuhi descendent, Dr. Jacquie Kidd, says some in the health sector identified they're not adequately reaching out to tangata whenua. Dr. Kidd, who's a senior lecturer at the University of Auckland, says many in the palliative care sector acknowledged that they don't know how to deal with tikanga and whanau Maori. <a href="http://www.radionz.co.nz/news/te-manu-korihi/251358/palliative-care-fails-some-maori">http://www.radionz.co.nz/news/te-manu-korihi/251358/palliative-care-fails-some-maori</a>

 'Health Literacy in Palliative Care,' Faculty of Medical & Health Sciences, University of Auckland, June 2014. [Noted in Media Watch, 4 August 2014, #369 (p.5)] <a href="https://cdn.auckland.ac.nz/assets/fmhs/faculty/ABOUT/newsandevents/docs/Health-literacy-in%20palliative-care-report.pdf">https://cdn.auckland.ac.nz/assets/fmhs/faculty/ABOUT/newsandevents/docs/Health-literacy-in%20palliative-care-report.pdf</a>

**N.B.** Additional articles on Māori beliefs and practices, and end-of-life care, are noted in Media Watch, 16 June 2014, #362 (p.8) and 17 March 2014, #349 (p.9).



# Who Cares? We Do!

Home page: <a href="http://www.worldday.org/">http://www.worldday.org/</a> Materials: <a href="http://www.worldday.org/materials/">http://www.worldday.org/materials/</a>

### Elder care in the U.K.

### Care home resident numbers remain static despite elderly population rise

U.K. (England & Wales) | Health Investor – 4 August 2014 - Despite an 11% rise in the number of people aged over 65 between 2001 and 2011 in England & Wales, the number of care home residents has hardly changed. According to figures from the Office for National Statistics (ONS) around 291,000 people were living in care homes in 2011, which is only 1,000 more than a decade earlier. Meanwhile, the population aged 65 and over has risen from 8.3 million to 9.2 million during this period. The ONS report attributes this to the fact elderly people are able to remain independent at home for longer due to factors such as improved population health and the increase in unpaid carers. Healthcare Property Consultants director Ian Wilkie, however, said that this is more likely to be down to a shortage in care homes. "There were 26,000 less beds in 2011 than in 2001. That is as a consequence of loss of capacity due to lack of funding, attrition of obsolete properties and lack of development finance to replace them. It led to people being left at home and receiving inadequate 15 minute home care visits that have been widely reported recently." <a href="http://www.healthinvestor.co.uk/(X(1)A(BuYDiVbmzwEkAAAAOGEwYjI0ZGMtMTljMS00ZGI1LWJmMmYtMmM0Mjg1YTg5MWZIZUpV7nkYvvpJfwLeZdiaaJlnEn01)S(djlkgm553m4wjv55tfxflp3a))/ShowArticle.aspx?lD=3466</a>

# **Specialist Publications**

'Half of ambulance trusts [in England & Wales] have no record of terminally ill patients' end-of-life wishes' (p.9), in *British Medical Journal*.

### Of related interest:

- U.K. | *The Guardian* 4 August 2014 'Delivering on Dilnot will the care cap work?' Sir Andrew Dilnot described the current system of funding for adult social care as "confusing, unfair and unsustainable" when he published his landmark reforms. People, the economist said, were unable to protect themselves from potentially catastrophic care costs and faced the risk of losing their home to pay for their care. He hoped that by introducing a financial cap on what people had to pay for their care during their lifetime and raising the financial threshold at which people become eligible for state financial help would bring peace of mind as they looked towards old age. But three years later, and nine months away from the first of the reforms being introduced, there is little evidence that his hopes and vision will be realised. http://www.theguardian.com/society/2014/aug/04/dilnot-will-care-cap-work
  - Fairer Care Funding, The Report of the Commission on Funding of Care & Support, July 2011. [Noted in Media Watch, 11 July 2011, #209 (p.5)] <a href="http://yhsccommissioning.org.uk/FairerCareFundingReport.pdf">http://yhsccommissioning.org.uk/FairerCareFundingReport.pdf</a>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ GERMANY | National Public Radio (U.S.) – 7 August 2014 – 'When and how to die: Germany debates whose choice it is.' Chancellor Angela Merkel's new government says the current approach to assisted suicide in Germany won't do. It is seeking a nationwide discussion this year to establish what euthanasia advocates fear will be a *de facto* ban on assisted suicide in Germany. Merkel's Christian Democratic Union political party has vowed to stop organizations and doctors it claims are profiting from vulnerable patients seeking to kill themselves. Euthanasia foes are also concerned that Germany is surrounded by countries with proeuthanasia and assisted suicide laws, some of which are being broadened. Switzerland, for example, allows foreigners in certain circumstances to come to the Alpine country and seek doctors' help in ending their lives. Detractors say Germans account for up to half of this socalled "suicide tourism." <a href="http://www.npr.org/blogs/parallels/2014/08/07/279046327/when-and-how-to-die-germany-debates-whose-choice-it-is">http://www.npr.org/blogs/parallels/2014/08/07/279046327/when-and-how-to-die-germany-debates-whose-choice-it-is</a>

# Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

### Prolonging life: Legal, ethical, and social dilemmas

ANNALS OF THE NEW YORK ACADEMY OF SCIENCES | Online – 30 July 2014 – The ability of modern medicine to prolong life has raised a variety of difficult legal, ethical, and social issues on which reasonable minds can differ. Among these are the morality of euthanasia in cases of deep coma or irreversible injury, as well as the dead donor rule with respect to organ harvesting and transplants. As science continues to refine and develop lifesaving technologies, questions remain as to how much medical effort and financial resources should be expended to prolong the lives of patients suspended between life and death. At what point should death be considered irreversible? What criteria should be used to determine when to withhold or withdraw life-prolonging treatments in cases of severe brain damage and terminal illness? To explore these complex dilemmas ... pediatrician Sam Shemie, hospice medical director Christopher P. Comfort, bioethicist Mildred Z. Solomon, and attorney Barbara Coombs Lee exam the underlying assumptions and considerations that ultimately shape individual and societal decisions surrounding these issues. http://onlinelibrary.wiley.com/doi/10.1111/nyas.12476/abstract?systemMessage=Wiley+Online+Library+will+be+disrupted+9th+Aug+from+10-

2+BST+for+essential+maintenance.+Pay+Per+View+will+be+unavailable+from+10-6+BST.&userlsAuthenticated=false&deniedAccessCustomisedMessage=

#### Of related interest:

- ANNALS OF THE NEW YORK ACADEMY OF SCIENCES | Online 24 July 2014 'Reversing death: The miracle of modern medicine.' Breakthroughs in emergency medicine have enabled science to halt and even reverse death. However, these advances have inadvertently led science into a domain that has traditionally been the purview of theology and philosophy. <a href="http://onlinelibrary.wiley.com/doi/10.1111/nyas.12475/abstract">http://onlinelibrary.wiley.com/doi/10.1111/nyas.12475/abstract</a>
- INTENSIVE CARE MEDICINE | Online 5 August 2014 ""No escalation of treatment" as a routine strategy for decision-making in the ICU.' Bioethicists have long argued against making a distinction between the ethical acceptability of withholding versus withdrawing treatment. The modern secular consensus was expressed concisely in a landmark 1983 report: "neither law nor public policy should mark a difference in moral seriousness between stopping and not starting treatment.' Nevertheless, it is easier to endorse this principle than to apply it. <a href="http://link.springer.com/article/10.1007/s00134-014-3421-6">http://link.springer.com/article/10.1007/s00134-014-3421-6</a>
- JOURNAL OF HUMANITIES & SOCIAL SCIENCE, 2014;19(4):119-122. 'End-of-life care Perceptions of public.' Medical technology has advanced to such an extent that it can keep people alive even if the last resort to make them well is not possible. Issues regarding these treatment measures will continue if patient autonomy is not respected. This study revealed that most of the people do not want to continue their life by means of supporting breathing machines if there is no hope of recovery. They would like to make their own decision for end-of-life care. <a href="http://www.scribd.com/doc/235876215/End-of-life-care-Perceptions-of-Public">http://www.scribd.com/doc/235876215/End-of-life-care-Perceptions-of-Public</a>

# Half of ambulance trusts [in England & Wales] have no record of terminally ill patients' end-of-life wishes

BRITISH MEDICAL JOURNAL | Online – 5 August 2014 – Half of ambulance trusts in England & Wales do not record patients' decisions on the end-of-life care treatment they wish to receive, a new [sic] report has found. The report ... found "considerable variation" in recording the treatment preferences of patients nearing the end of life, such as "do not attempt resuscitation" decisions. <a href="http://www.bmj.com/content/349/bmj.g5015">http://www.bmj.com/content/349/bmj.g5015</a>

 'Are policies in place within Ambulance Trusts' services to allow patients' end-of-life wishes to be appropriately recorded and acted upon?' Compassion in Dying,' May 2012. <a href="http://www.compassionindying.org.uk/sites/default/files/Amb%20FOI%20report.pdf">http://www.compassionindying.org.uk/sites/default/files/Amb%20FOI%20report.pdf</a>

Cont.

Noted in Media Watch, 27 January 2014, #342 (p.11):

■ INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2014;20(1):37-44. 'Challenges U.K. paramedics currently face in providing fully effective end-of-life care.' Paramedics play an integral part in community end-of-life care (EoLC) in the U.K., especially given the lack of out-of-hours cover by palliative care specialists. This article highlights some of the barriers to effective paramedic EoLC provision and introduces examples of collaborative work in the U.K. that aim to overcome these. Given the similarities in the international evolution of paramedic education, readers from other countries will be able to relate to these findings. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=102856;article=IJPN 20 1 37 44

### Elder care in the U.S.

# For-profit Medicare home health agencies' costs appear higher and quality appears lower compared to non-profit agencies

HEALTH AFFAIRS, 2014;33(8):1460-1465. For-profit ... home health agencies were banned from Medicare until 1980, but now account for a majority of the agencies that provide such services. The authors ... assessed the performance of for-profit and non-profit home health agencies. For-profit agencies scored slightly but significantly worse on overall quality indicators compared to non-profits... Notably, for-profit agencies scored lower than non-profits on the clinically important outcome "avoidance of hospitalization" ... Scores on quality measures were lowest in the South, where for-profits predominate. Compared to non-profits, for-profit agencies also had higher costs per patient (\$4,827 versus \$4,075), were more profitable, and had higher administrative costs. Findings [of this study] raise concerns about whether for-profit agencies should continue to be eligible for Medicare payments and about the efficiency of Medicare's market-oriented, risk-based home care payment system. http://content.healthaffairs.org/content/33/8/1460.abstract?rss=1

### **Media Watch: Editorial Practice**

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy and research tool.

# **Distribution**

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### **Links to Sources**

- 1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
- 2. Links often remain active, however, for only a limited period of time.
- 3. Access to a complete article, in some cases, may require a subscription or one-time charge.
- **4.** If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
- **5.** Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### **Something Missed or Overlooked?**

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

### End-of-life care in India

# End of life care policy for the dying: Consensus position statement of Indian Association of Palliative Care

INDIAN JOURNAL OF PALLIATIVE CARE. 2014;20(3):171-181. A review of country reports, observational studies and key surveys demonstrates that end-of-life care (EOLC) in India is delivered ineffectively, with a majority of the Indian population dying with no access to palliative care at end of life and essential medications for pain and symptom control. Limited awareness of EOLC among public and health care providers, lack of EOLC education, absent EOLC policy and ambiguous legal standpoint are some of the major barriers in effective EOLC delivery. Access to receive good palliative and EOLC is a human right. All patients are entitled to a dignified death. This position paper is an effort to achieve this goal by developing a nationwide uniform EOLC policy, creating an appropriate environment for its provision and encouraging the participation of all the stake holders such that a common goal is attained. The position paper is envisaged to support and facilitate those health care providers who aim to make a difference in lives of the patients who are dving. http://www.ipalliativecare.com/article.asp?iss n=0973-

1075;year=2014;volume=20;issue=3;spage= 171;epage=181;aulast=Macaden

# Of related interest:

■ INDIAN JOURNAL OF PALLIATIVE CARE, 2014;20(3):201-207. 'Creation of minimum standard tool for palliative care in India and self-evaluation of palliative care programs using it.' In 2006, Pallium India assembled a working group to develop minimum standards. Forty-nine (57%) [of] palliative care organizations responded [to a request for] self-evaluation of services based on the standards tool. The majority ... met most of the standards identified as essential by the working group. <a href="http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2014;volume=20;issue=3;spage=201;epage=207;aulast=Rajagopal">http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2014;volume=20;issue=3;spage=201;epage=207;aulast=Rajagopal</a>

# The truth shall set you free: Saying an honest "goodbye" before a loved-one's death

INTERNATIONAL JOURNAL OF PSYCHOTHERAPY, 2014;18(2):72-79. Many people suffer from anticipatory grief before the death of a loved one. This article is based on the Gestalt Therapy premise that it is necessary to have a contactful "hello" before one can have a genuine "goodbye." It reviews some of the relevant literature, defines the premise of "unfinished business," describes the therapeutic benefits of fantasy, and provides a case example using the "empty chair" method. The psychotherapy described is about creating an opportunity for the expression of feelings, making interpersonal contact, and "truth telling" before the other person dies. <a href="http://www.scottdmiller.com/wp-content/uploads/2014/07/Why-Most-Therapists-are-Average-German-2014.pdf#page=72">http://www.scottdmiller.com/wp-content/uploads/2014/07/Why-Most-Therapists-are-Average-German-2014.pdf#page=72</a>

# Indian Association of Palliative Care recommendations

Government of India to take urgent steps towards a legislation supporting good EOLC, and all hospitals and health care institutions to have a working EOLC policy

Providing a comprehensive care process that minimizes physical and non physical symptoms in the end of life phase and ensuring access to essential medications for pain and symptom control

Palliative care and EOLC to be part of all hospital and community/home based programs

Standards of palliative and EOLC as established by appropriate authorities and Indian Association of Palliative Care met and standards accredited and monitored by national and international accreditation bodies

All health care providers with direct patient contact are urged to undergo EOLC certification, and EOLC training should be incorporated into the curriculum of health care education.

# Shared decision-making about end-of-life care for heart failure patients with an implantable cardioverter defibrillator: A national cohort study

JOURNAL OF CARDIAC FAILURE, 2014;20(8):S11. ICD [implantable cardioverter defibrillator] recipients with HF [heart failure] hold many perceptions about the ICD at end-of-life that could interfere with effective decision-making. Without better knowledge about their ICD and its performance at the end-of-life, or without discussions with doctors and family members about these issues, HF patients with an ICD are ill-prepared to engage in shared decision-making about their ICD and its use at the end-of-life. <a href="http://www.onlinejcf.com/article/S1071-9164(14)00269-3/fulltext">http://www.onlinejcf.com/article/S1071-9164(14)00269-3/fulltext</a>

Selected articles on defibrillator deactivation in end-of-life care noted in past issues of Media Watch:

- THE PATIENT PATIENT-CENTERED OUTCOMES RESEARCH | Online 26 March 2014 'Making decisions about implantable cardioverter-defibrillators from implantation to end of life: An integrative review of patients' perspectives.' Common themes from patients' perspectives were the influence of the patient-practitioner consultation on knowledge uptake, patients' decision-making preference, and their desire to live. Patients faced with decisions often misunderstood the functionality of their ICD, or overestimated its benefit. They expressed mixed preferences for the desire to be involved in decisions. [Noted in Media Watch, 21 April 2014, #354 (p.13)] http://link.springer.com/article/10.1007/s40271-014-0055-2#
- CURRENT HEART FAILURE REPORTS | Online Accessed 18 March 2014 'Ethical challenges of deactivation of cardiac devices in advanced heart failure.' While patients with ICDs are routinely counseled with regard to the benefits of ICDs, they have a poor understanding of the options for device deactivation and related ethical and legal implications. [Noted in Media Watch, 24 March 2014, #350 (pp.9-10)] <a href="http://link.springer.com/article/10.1007/s11897-014-0194-8">http://link.springer.com/article/10.1007/s11897-014-0194-8</a>

**N.B.** Footnoted in this issue of Media Watch is additional articles on the issue of defibrillator deactivation in end-of-life care. Other articles on the subject are also noted in Media Watch, 27 February 2012, #242 (p.13).

#### Of related interest:

■ JOURNAL OF CARDIAC FAILURE, 2014;20(8):S118. 'End-of-life perceptions of congestive heart failure outpatients.' Evidence suggests heart failure patients infrequently discuss their end-of-life preferences with their cardiologist and they often have a poor understanding of their prognosis. <a href="http://www.onlinejcf.com/article/S1071-9164(14)00566-1/abstract">http://www.onlinejcf.com/article/S1071-9164(14)00566-1/abstract</a>

### End-of-life care in the U.S.

### Can hospices predict which patients will die within six months?

JOURNAL OF PALLIATIVE MEDICINE, 2014;17(8):894-898. Among 126,620 patients admitted to 10 hospices, 118,532 (93.6%) died within 6 months. In a multivariable logistic regression model, five characteristics were independent predictors of 6-month mortality. For instance, patients younger than 65 years were less likely to die within 6 months. Conversely, male patients were more likely to die within 6 months. After adjusting for other variables in this model, there were several sub-groups with a low probability of 6-month probability... However, 95% confidence intervals of these 6-month mortality predictions extended above 50%. Hospices might use several variables to identify patients with a relatively low risk for 6-month mortality and who therefore may become ineligible to continue hospice services if they fail to show significant disease progression. http://online.liebertpub.com/doi/full/10.1089/jpm.2013.0631

Noted in Media Watch, 23 June 2014, #363 (p.12):

■ JOURNAL OF PALLIATIVE MEDICINE | Online – 16 June 2014 – 'Patients surviving six months in hospice care: Who are they?' On 1 January 2011, the Centers for Medicare & Medicaid Services began requiring U.S. hospices to conduct a "face-to-face" assessment of eligibility for continued hospice care with patients entering their third certification period (180 days after initial enrollment). <a href="http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0512">http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0512</a>

# Thank you for your lovely card: Ethical considerations in responding to bereaved parents invited in error to participate in childhood cancer survivorship research

MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 29 July 2014 – This article presents a series of cases of parents bereaved by childhood cancer who unintentionally received invitations to participate in survivorship research. The authors explore six ethical considerations, and compare their experiences with that described previously. Considerations include the sharing of confidential information with external parties to confirm past patients' vital status and appropriate researcher responses to bereaved parents. The management of researchers' emotional safety when working with illness populations and the fact that study invitations can elicit grief responses in non-bereaved families are discussed. <a href="http://link.springer.com/article/10.1007/s11019-014-9587-4#">http://link.springer.com/article/10.1007/s11019-014-9587-4#</a>

### End-of-life care in Thailand

### Factors predicting the effectiveness of palliative care in patients with advanced cancer

PALLIATIVE & SUPPORTIVE CARE | Online – 5 August 2014 – Significant predictors of the effectiveness of palliative care in patients with advanced cancer [i.e., study participants] were spiritual well-being and palliative care strategies: a combination of pharmacological and psychosocial care; mind-body intervention and spiritual care; physical management; and, traditional medicine, herbal treatment and diet management. Patients who experienced spiritual well-being and employed a variety of palliative care strategies experienced enhanced effectiveness of palliative care. <a href="http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9315315&fulltext">http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9315315&fulltext</a> Type=RA&fileId=S1478951514000856

Noted in Media Watch, 6 January 2014, #339 (p.10):

■ JOURNAL OF PALLIATIVE CARE, 2013;29(3):133-139. 'Palliative care personnel and services: A national survey in Thailand 2012.' Research on palliative care services in Thailand is incomplete. The overall response rate of government hospitals was 61% (537 of 882 hospitals). Of these, 59% reported that they had personnel trained in palliative care; the majority had received less than a week of such training. In all, 60% of the hospitals reported that they offered palliative care services, but 25% of these services were delivered by staff who had no palliative care training. <a href="http://www.ncbi.nlm.nih.gov/pubmed/24380211">http://www.ncbi.nlm.nih.gov/pubmed/24380211</a>

Noted in Media Watch, 9 July 2012, #261 (p.7):

SOCIAL SCIENCE & MEDICINE, 2012;75(5):836-844. 'On ethical locations: The good death in Thailand, where ethics sit in places.' In Northern Thailand, many feel that it is ethical to withdraw life support in the home, but unethical to withdraw it in the hospital. This is because the place of death is partly responsible for the quality of rebirth. Hospitals, on one hand, are powerful for saving lives; but as places to die, they are amoral, dangerous, devoid of ceremonial history and haunted by spirits. Homes, on the other hand, are optimal for dying because they are imbued with moral power from a history of beneficial ceremony and family living. http://www.sciencedirect.com/science/article/pii/S0277953612003383

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### American Academy of Pediatrics Policy Statement

# Integration of palliative care into the care of children with serious illness

PEDIATRICS IN REVIEW, 2014;35(8):318-326. The 2013 American Academy of Pediatrics Policy Statement 'Pediatric Palliative Care and Hospice Care: Commitments, Guidelines, and Recommendations' urges broader integration of palliative care into overall medical care plans not only for terminally ill infants and children but also for those with life-threatening or life-shortening illnesses. Despite supportive federal legislation, the Academy's recommendations have not been implemented consistently because of inadequate training, lack of funding, entrenched professional attitudes, and lack of an evidence base for assessments and interventions. To overcome these barriers, pediatric health care clinicians should educate themselves, their patients, their practices, and their health care systems on the benefits of earlier palliative care intervention. http://pedsinreview.aappublications.org/content/35/8/318.extract

 'Pediatric Palliative Care and Hospice Care Commitments, Guidelines and Commitments,' Pediatrics, 2013;5(1):966-972. [Noted in Media Watch, 4 November 2013, #330 (p.13)] http://pediatrics.aappublications.org/content/132/5/966.full.pdf+html

**N.B.** Several articles on different aspects of pediatric palliative care are noted in Media Watch 4 August 2014, #369 (p.14) and 14 July 2014, #366 (pp.10-11).

# Inadequate involvement of general practitioners in end of life's decisions in an intensive care unit

LA PRESSE MÉDICALE | Online – 24 July 2014 – Patients' general practitioners (GPs) could be relevant consultants for collegial decisions of withholding or withdrawing treatment (WWT) defined by the Léonetti law. The authors, therefore, studied their implication by intensivists in end-of-life decisions and collected their feelings. Their wishes for the coming law revision were also investigated. Two GPs out of three reported that they never participate in such decisions for their patients. All uninvolved GPs did not contribute because intensivists did not consult them. Only 43.7% of GPs were contacted by intensivists during the stay and 21.9% at the discharge or death of their patient. Regarding uninvolved GPs, their participation could have changed WWT's decisions made for two patients (7.7%). Most respondents felt available (78.1%) and skilled (81.2%) to participate in this kind of decision. A third was also questioned by the patient's family about it. Only 21.7% of GPs report to be familiar with the French end-of-life legislation. In case of a next revision, two thirds considered important to make the use of GPs obligatory in such decisions. http://www.sciencedirect.com/science/article/pii/S075549821400342X

**N.B.** French language article. The 2005 Léonetti Law Act established the right in France to "let die." The law opposes the "unreasonable obstinacy" of undertaking or continuing "unnecessary or disproportionate" treatment, "with no other effect than maintaining life artificially."

### CPR and hospice: Incompatible goals, irreconcilable differences

PROGRESS IN PALLIATIVE CARE | Online – Accessed 8 August 2014 – The purpose of this paper is to challenge the current acceptance of cardiopulmonary resuscitation (CPR) in hospice care. The authors contend CPR should not be part of the hospice experience because it is contrary to the goals and mission of hospice. While understanding the [U.S.] Medicare conditions of participation do not allow refusal of hospice enrollment based on the presence (or absence) of advance directives, they propose a transparent, common sense approach for hospices to consider when faced with a hospice eligible patient who desires CPR despite medical advice to the contrary. http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.00000000098

# Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices

PSYCHO-ONCOLOGY | Online – 7 August 2014 – Family caregivers do not generally concur with patients in their preferences, nor do they reliably predict PP [patient preferences]. Open dialogue between patient and family caregivers would reduce the discrepancy. More emphasis on incorporating family caregivers in EOL [end-of-life] communication is needed from clinical, research, and training perspectives. While patients and family caregivers [i.e., study participants] had wide spectra of preferences, patients significantly preferred disclosure, direct disclosure by a physician, and palliative care options. Family caregiver predictions were similar to PP with regard to terminal disclosure, but significantly different with regard to family involvement in the disclosure process and EOL choices. The concordances of PP and FCP [family caregiver preferences], and those of PP and FCPPP [family caregiver predictions of patient preferences], were poor. http://onlinelibrary.wiley.com/doi/10.1002/pon.3631/abstract

### Of related interest:

■ SUPPORTIVE CARE IN CANCER | Online – 3 August 2014 – 'Decision making at the end of life – cancer patients' and their caregivers' views on artificial nutrition and hydration.'

Deciding on artificial nutrition and hydration (ANH) at the end of life (EoL) may cause concerns in patients and their family caregivers but there is scarce evidence regarding their preferences. Therefore, the aim of this study was to assess the impact of factors associated with ANH decision making. Cancer patients and their relatives [i.e., study participants] have similar preferences regarding ANH at the EoL, but relatives are reluctant to withhold AH if deciding for their loved one. <a href="http://link.springer.com/article/10.1007/s00520-014-2337-6">http://link.springer.com/article/10.1007/s00520-014-2337-6</a>

Noted in Media Watch, 24 March 2014, #350 (p.7):

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 17 March 2014 – 'What influences attitudes towards clinically assisted hydration in the care of dying patients? A review of the literature.' Developing international evidence suggests that cultural norms and ethical principles of a family, population or healthcare environment influence attitudes towards CAH [clinically assisted hydration], particularly where CAH has symbolic meaning; representing care, hope and trust. <a href="http://spcare.bmj.com/content/early/2014/03/17/bmjspcare-2013-000562.abstract">http://spcare.bmj.com/content/early/2014/03/17/bmjspcare-2013-000562.abstract</a>

### Death as a social harm

THE SOUTHERN JOURNAL OF PHILOSOPHY, 2014;52(S1):53-65. Lately there has been increased attention to the philosophical issues that death raises, but the focus remains individualistic. Death is philosophically puzzling. Death is thought to be bad for the individual who dies, but there is no one there to experience death as a harm. The author argues that the harm of death is a social harm. Of course, social relationships are fundamentally changed when any member of a social group dies. Death is harmful for those left behind. The problem is not just that social relations are harmed by the loss of a loved one. The very meaning and value of our lives and projects are shaped by social relations. By recognizing death as a social harm that many animals, human and non-human, experience, we may be better prepared for the work of mourning. <a href="http://onlinelibrary.wiley.com/doi/10.1111/sjp.12064/abstract;jsessionid=E2E5E36FB8CEA81F0A5869A8F2A4DAF9.f01t04?systemMessage=Wiley+Online+Library+will+be+disrupted+9th+Aug+from+10-2+BST+for+essential+maintenance.+Pay+Per+View+will+be+unavailable+from+10-6+BST.&userlsAuthenticated=false&deniedAccessCustomisedMessage=

### Of related interest:

ANNALS OF THE NEW YORK ACADEMY OF SCIENCES | Online – 24 July 2014 – 'Experiencing death: An insider's perspective.' Technological advances in resuscitation science have now added an intriguing new chapter to the literature of out-of-body or near-death experiences by eliciting detailed and vivid accounts of those who have approached the threshold of death. <a href="http://onlinelibrary.wiley.com/doi/10.1111/nyas.12473/abstract">http://onlinelibrary.wiley.com/doi/10.1111/nyas.12473/abstract</a>

# Assisted (or facilitated) death

Representative sample of recent news media coverage:

ANNALS OF THE NEW YORK ACADEMY OF SCIENCES | Online – 31 July 2014 – 'Oregon's experience with aid in dying: Findings from the death with dignity laboratory.' With passage of the Death with Dignity Act in 1993, Oregon became the first jurisdiction to authorize and regulate aid in dying. Data from that experience are comprehensive and bountiful, and answer a multitude of questions and concerns about whether the benefits of recognizing the medical practice of aid in dying justify the risks. An exhaustive description of findings from Oregon's aid-in-dying experience is beyond the scope of this or any single article on the subject. http://onlinelibrary.wiley.com/doi/10.1111/nyas.12486/abstract

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### **Media Watch Online**

#### International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <a href="http://hospicecare.com/about-iahpc/newsletter/2014/5/media-watch/">http://hospicecare.com/about-iahpc/newsletter/2014/5/media-watch/</a>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <a href="http://www.ipcrc.net/archive-global-palliative-care-news.php">http://www.ipcrc.net/archive-global-palliative-care-news.php</a>

PALLIATIVE CARE NETWORK COMMUNITY: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

PALLIMED (Hospice & Palliative Medicine Blog): <a href="http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html">http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html</a> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

#### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <a href="http://centres.sg/updates/international-palliative-care-resource-center-media-watch/">http://centres.sg/updates/international-palliative-care-resource-center-media-watch/</a>

#### Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <a href="http://palliativecarewa.asn.au/site/helpful-resources/">http://palliativecarewa.asn.au/site/helpful-resources/</a> [Scroll down to 'International Websites' and <a href="http://www.ipcrc.net/archive-qlobal-palliative-care-news.php">http://www.ipcrc.net/archive-qlobal-palliative-care-news.php</a> to access the weekly report]

# Canada

ONTARIO | Central Regional Hospice Palliative Care Program: http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health\_Practitioners/resources.htm?mediawatch=1

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpcconnection.ca/newsletter/inthenews.html

ONTARIO | Mississauga Halton Palliative Care Network: http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1

ONTARIO | Palliative Care Consultation Program (Oakville): <a href="http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/">http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/</a> [Scroll down to 'Additional Resources']

### Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <a href="http://www.eapcnet.eu/Themes/Organization/Links.aspx">http://www.eapcnet.eu/Themes/Organization/Links.aspx</a> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: http://www.hospicehaz.hu/en/training/ [Scroll down to 'Media Watch']

U.K. | Omega, the National Association for End-of-Life Care: <a href="http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c">http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c</a>

- BANGLADESH JOURNAL OF BIOETHICS, 2014;5(2):61-67. 'Shortcomings and inadequacies of autonomy argument for euthanasia.' Patient autonomy has a critical role in making decisions in medical practice and it is accepted by international conventions on health care and various national medical codes. However, pertaining to terminally ill patients, this right becomes very problematic in regards to end-of-life decisions. Utilitarian ethicists motivated by materialistic worldview and individualism have made patient autonomy based arguments for the permissibility of active euthanasia. An appraisal of pro-euthanasia arguments that include the best interest, golden rule, and autonomy is made in this paper. The best interest and golden rule arguments are based on subjective moral judgment thus failing the universalization test. http://www.banglajol.info/index.php/BIOETHICS/article/view/19620
- BMC HEALTH SERVICES RESEARCH | Online 16 July 2014 'Nationwide survey to evaluate the decision-making process in euthanasia requests in Belgium: Do specifically trained second physicians improve quality of consultation?' Of the 244 physicians [i.e., study participants] who indicated having received a euthanasia request, seventy percent consulted a second physician; in 30% [of requests] this was with a LEIF [Life End Information Forum] physician. Compared to non-LEIF physicians, LEIF physicians were more often not a colleague (69% vs. 42%) and not a co-attending physician (89% vs. 66%). http://www.biomedcentral.com/1472-6963/14/307
- EUROPEAN PSYCHIATRY, 2014;29(S1):1. 'Physician-assisted suicide and the role of the psychiatrists. a medical ethical analysis.' The authors argue that psychiatrists are particularly well-suited to differentiate autonomous and non-autonomous suicide plans based on their expertise in the field of suicidology and in competence assessment. From an ethical point of view, the involvement of psychiatrists can thus contribute to quality assurance of a legalized practice of PAS, benefit the patient autonomy at the end of life and minimize risks of abuse. http://www.europsy-journal.com/article/S0924-9338(14)78707-3/abstract
- JOURNAL OF MEDICAL ETHICS | Online 31 July 2014 'Quality-adjusted life year, euthanasia, and the puzzle of death.' This paper considers the problems that arise when death, a philosophically difficult concept, is incorporated into healthcare metrics, such as the quality-adjusted life year (QALY). These problems relate closely to the debate over euthanasia and assisted suicide because negative QALY scores can be taken to mean that patients would be "better off dead." There is confusion in the literature about the meaning of 0 QALY, which is supposed to act as an "anchor" for the surveyed preferences on which QALYs are based. In the context of the debate over euthanasia, the QALY assumes an ability to make meaningful comparisons between life-states and death. Not only is this assumption questionable, but the ethical debate is much more broad than the question of whether death is preferable to a state of living. http://ime.bmj.com/content/early/2014/07/31/medethics-2014-102060.short
- THE PHARMACEUTICAL JOURNAL (U.K.) | Online 4 August 2014 'The Royal Pharmaceutical Society policy on assisted suicide addresses many questions.' Although it was good to see an update on the progress of the Westminster private members' bill on assisted dying reported in last weeks' editorial we were disappointed that no mention was made of the Royal Pharmaceutical Society (RPS) policy and the amount of work RPS staff have already undertaken to support the profession, should this legislation be passed. The RPS policy was developed across the three national boards, with an expert working group from all sectors of the profession, and a member reference group. Although taking a neutral stance to accommodate the spectrum of views among our members, the policy addresses many of the questions ... raised in the editorial, providing guidance, support and a framework for the finer details you mention, including the requirement for robust protocols, governance and a conscience clause. <a href="http://www.pharmaceutical-journal.com/opinion/correspondence/the-rps-policy-on-assisted-suicide-addresses-many-questions/20066056.article">http://www.pharmaceutical-journal.com/opinion/correspondence/the-rps-policy-on-assisted-suicide-addresses-many-questions/20066056.article</a>
  - Royal Pharmaceutical Society policy statement on assisted suicide. January 2013. http://www.rpharms.com/policy-pdfs/assisted-suicide---201301.pdf

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